Exploring the psychometric properties of health and wellbeing measures used with adolescents experiencing intellectual disabilities: a systematic review.

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Exploring the psychometric properties of health and wellbeing measures used with adolescents experiencing intellectual disabilities: a systematic review

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Review question

1. What measures are being/have been used to assess health and wellbeing of adolescents (aged 11-16) with intellectual disabilities (ID)?
2. What is the methodological quality of these health and wellbeing measures for use with adolescents (aged 11-16) with ID?
3. What measures work best for assessing health and wellbeing of adolescents (aged 11-16) with ID?

Searches

A systematic database search will be performed using the Psychological Information Database (PsycINFO), Cumulative Index of Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis Retrieval System Online (MEDLINE), and Education Resources Information Center (ERIC).

Key terms pertaining to intellectual disability, health and wellbeing, psychometric properties, measures and adolescence will be used (see search strategy for full search strings for each database).

Studies published from January 2000 to February 2021 and available in the English language will be considered.

Additional search strategy information can be found in the attached PDF document (link provided below).

Types of study to be included

Inclusion: Quantitative and mixed-methods studies, grey literature.
Exclusion: Review papers, editorials, or case studies.

Condition or domain being studied

An ID is a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, as expressed in conceptual, social, and practical adaptive skills (AAIDD, 2008). It is a generalized disorder, which encompasses a wide array of cognitive and behavioural deficiencies; and affects the individuals in all areas of life (AAIDD, 2010). The severity of ID is classified into four types based on an intelligence quotient (IQ) test (i.e., mild, moderate, severe, and profound ID) (AAIDD 2010).

Participants/population

Inclusion: The sample will include adolescents between the ages of 11 and 16. If a study includes a broader age range encompassing 11-16-year-olds and if it is possible data will be extracted for only the targeted age groups.
Participants must have an intellectual disability diagnosis (mild, moderate, severe, or profound).

Exclusion: Young children (aged 10 or younger), adults (17 years or above) and elderly people (over 70) will be excluded. Studies will be excluded if it is not clear whether participants have an intellectual disability, or where they have other conditions (i.e., autism, epilepsy, or physical disabilities) without specifically noting that they also have an intellectual disability.

Intervention(s), exposure(s)

Not applicable (this review will explore the psychometric properties of health and wellbeing measures used with adolescents experiencing intellectual disabilities).

Comparator(s)/control

Not applicable.

Context

Inclusion: Studies from all countries as long as they are available in an English translation.
Exclusion: Studies that cannot be translated into English.

Main outcome(s)

To identify health and wellbeing measures used with adolescents (aged 11-16) who have an intellectual disability.
Determine the psychometric properties of health and wellbeing measures used with adolescents (aged 11-16) who have an intellectual disability.

Measures of effect

Not applicable.

Additional outcome(s)

None.

Measures of effect

Not applicable.

Data extraction (selection and coding)

Titles and/or abstracts of studies retrieved using the database searches and those from additional sources will be screened independently in Covidence by two review authors (SM and JD) to identify studies that potentially meet the inclusion criteria outlined above. The full text of these potentially eligible studies will be retrieved and independently assessed for eligibility by two review authors. Any disagreement between them over the eligibility of studies will be resolved through discussion with a third review author (MM).
A standardized, pre-piloted form will be used to extract data from the selected studies for assessment of study quality and evidence synthesis. Two review authors will record information related to: (1) study characteristics (i.e., study setting; study population, study sample (n); study methodology) (2) instrument characteristics (i.e., reporter (self and/or proxy); type of instrument; format of the instrument (i.e., number of items and response formats), psychometric properties of the instrument (e.g., Cronbach's alpha, reliability analysis); and the results of the measure/study). Where needed, we will contact authors for original data with a maximum of three contact emails: once a month over three months.

Risk of bias (quality) assessment

Two review authors will assess the methodological quality by applying the COSMIN Risk of Bias Checklist (Mokkink, de Vet et al., 2018). The COSMIN Checklist contains ten boxes with standards for PROM development (box 1) and for nine measurement properties: including content validity (box 2); structural validity (box 3); internal consistency (box 4); cross-cultural validity\measurement invariance (box 5); reliability (box 6); measurement error (box 7); criterion validity (box 8); hypotheses testing for construct validity (box 9); and responsiveness (box 10). Only checklist items that are assessed in each included study will be completed since not all measurement properties are evaluated in all articles. For each study, an overall judgement will be provided on the quality of the particular study. We will use a four-point rating system where each standard within a COSMIN box will be rated as 4 = 'very good', 3 = 'adequate', 2 =

'doubtful' or 1 = 'inadequate'. The total score of methodological quality ratings per psychometric property will be presented as a percentage of the ratings: inadequate (0%–25%); doubtful (25.1%–50%); adequate (50.1%–75%); and very good (75.1%–100%). Two review authors will rate the methodological quality independently, and any discrepancies will be resolved by consensus.

Strategy for data synthesis

The result of each single study on a measurement property will be rated against the updated criteria for good measurement properties on which consensus will be achieved by the two review authors. Each result will be rated as either: sufficient (above the quality criteria threshold: +); insufficient (below the quality criteria threshold: -); or indeterminate (less robust data that do not meet the quality criteria:?) using the predefined criteria for good psychometric properties. A 75% agreement rate will be used that is for an overall sufficient (+) or insufficient (-) rating on a psychometric property, 75% or more of the studies reporting the psychometric property must be sufficient (+) or insufficient (-). Otherwise, for an overall inconsistent (±) rating, less than 75% of studies will show the same rating, and for overall indeterminate (?) rating, all studies will be indeterminate (?).

The evidence will be summarised, and the quality of the evidence (i.e., the total body of evidence used for the overall ratings on each psychometric property of an instrument) will be graded as high, moderate, low, or very low using the Grading of Recommendations, Assessment, Development and Evaluations guidelines (Prinsen et al., 2018).

The selection of instruments and recommendation of suitable instruments for future use will be based on a combining overall rating results of each psychometric property (Step 2) and grading results (Step 3) (Prinsen et al., 2018). Each instrument will be classified into three recommendation categories: (A) most suitable (i.e., instruments with high-quality evidence for sufficient content validity in any aspects of relevance, comprehensiveness, and comprehensibility, and at least low-quality evidence for sufficient internal consistency); (B) promising but need further validation studies (i.e., instruments categorized not in A or C); and (C) not recommendable (i.e., instruments with high quality evidence for an insufficient psychometric property).

Analysis of subgroups or subsets

None planned.

Contact details for further information

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Type and method of review

Methodology, Systematic review

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Conflicts of interest

Language

English

Country

Northern Ireland

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Adolescent; Adolescent Health; Humans; Intellectual Disability; Mental Health; Psychometrics; Quality of Life; Surveys and Questionnaires

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09 March 2021

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

10 March 2021